



The Health Care Law: Good News for Caregivers

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About 52 million Americans take care of a spouse, a child, a parent, another relative, or a loved one at some point in time during the course of a year.¹ Maybe you are one of the millions of women and men who are caregivers. If so, you know that the responsibilities of caregiving can take a toll, both emotionally and financially. The typical caregiver loses \$110 in wages and benefits a day, postpones their own medical care, and cuts back on household spending.²

Help for caregivers and those they care for is on the way. The health care law that was passed in March 2010 (also known as the Affordable Care Act) includes several measures that will mean more support for caregivers, as well as improved quality of care and more protections for the seniors and people with disabilities that they care for. This piece discusses those measures.

More Support for Caregivers

The health care law improves support for caregivers in several ways. First, there are new programs to help ensure that there is an **adequate supply of well-trained long-term care workers**. That means there will be more outside professional support options to relieve you so you can tend to other responsibilities or take a needed rest. Second, there are new programs to provide consumers who are eligible for Medicaid with **better coverage of in-home assistance**, as well as a **new long-term care insurance program**. Those programs will make long-term care more affordable for caregivers and those they care for.

■ Building the Long-Term Care Workforce

Many caregivers rely on professional long-term care workers, like home health aides, personal attendants, and nurses' aides, to help them with their caregiving responsibilities. However, as you may know firsthand, it isn't always easy to get the help you need. Part of the reason is that there is a national shortage of long-term care workers.³ The health care law addresses long-term care workforce issues in a way that hasn't been done before. It includes programs that are designed to increase the supply of well-trained long-term care workers, and it takes steps to make sure that we have enough long-term care workers going forward. The health care law does the following:



Advocacy Tip

The workforce planning programs that are included in the new law will need to be funded. Advocating for full funding for implementation of the Affordable Care Act will help make sure these programs move forward.

- Establishes training programs with grants to encourage people to go into—and stay in—the long-term care workforce;
- Develops model training programs to make sure that the workforce can meet the demands of a growing number of consumers;
- Establishes a national panel of experts to advise the Department of Health and Human Services on workforce issues related to personal care attendants; and
- Establishes a commission to make recommendations to Congress on national health care workforce issues, including issues related to long-term care workers.

These measures will result in a larger, more stable pool of workers who are available to help caregivers and those they care for.

■ **Encouraging States to Expand the Home- and Community-Based Care They Offer in Medicaid**

Long-term care is extremely expensive, and it is not usually covered by Medicare or most other health insurance. Many people who need long-term care use up their savings paying for care, often reaching the point where they become eligible for Medicaid (the state and federally funded health coverage program for people with low incomes). The federal government requires state Medicaid programs to pay for nursing home care. However, states do not have to cover most long-term services that are provided outside of an institutional setting, known as “home- and community-based services.” As a result, in many places, there are limited options for Medicaid-eligible seniors and people with disabilities to get affordable long-term care in the community. To avoid moving to a nursing home, many have to rely entirely on informal caregivers.

The health care law includes two new optional programs that give states financial incentives to expand the home- and community-based services they offer in Medicaid.

1. **The State Balancing Incentive Payments Program** gives participating states added federal money to invest in expanding the options for home- and community-based care in Medicaid overall.



Advocacy Tip

The training grants for long-term care workers who provide direct patient care will need to be funded through the budget process. Advocating for full funding for implementation of the Affordable Care Act will help make sure that these grant programs are there to help build the long-term care workforce.



Advocacy Tip

If your state might be eligible for the State Balancing Incentive Payments Program (see the brief, *The Affordable Care Act: Provisions that Will Help Caregivers*, for details), encourage it to apply. Make sure that your state legislators and Medicaid officials know the benefits of the added federal Medicaid match that the state could receive for participating in the program. Applying for this program makes sense particularly if your state is in the process of trying to build better administrative systems to expand its use of non-institutional care in Medicaid, because this program could provide federal support for something the state is already doing.

2. **The Community First Choice Option** is a new program that gives states added federal money specifically for providing personal attendant services in Medicaid.⁴

In states that take up either or both options, Medicaid consumers should see an expanded range of home care options. If you're taking care of someone who has Medicaid, that means more options to help you, as well. And even if the person you're caring for is not in Medicaid, these programs will still help, because in states that increase their investments in community-based care in Medicaid, more of those services are available for everyone.

- **More Resources to Help You Make Good Choices and Find the Help You Need**

It isn't just getting the help you need that can be hard. If you're taking care of someone who needs long-term services, you may not even know where to start looking for help. Every state has aging and disability resource centers, which are designed to help consumers who need long-term services (or their caregivers) find information on what care options are available, how to find services that will best match what's needed, and what benefits and funding sources are available. The health care law gives these centers added funding, which will help them better serve caregivers like you.

- **For Help in the Future, a New Long-Term Care Insurance Program**

The health care law also includes a new voluntary long-term care insurance program, the Community Living Assistance Services and Supports program, or CLASS. Working adults will be eligible to sign up for the program. They will need to be enrolled for five years before they can receive benefits. For enrollees who need long-term services, the program will provide a cash benefit that will average at least \$50 a day, which comes to \$18,250 a year. CLASS participants who receive benefits will be able to use those benefits any way they see fit to pay for long-term services, including paying caregivers.



Advocacy Tip

States have to apply for the Community First Choice Option. Make sure that your state legislators and Medicaid officials know that advocates support the state adopting this program. You will also want to make sure that they know what the added federal Medicaid match could mean for your state and how many people might benefit from the program. (See the brief, *The Affordable Care Act: Provisions that Will Help Caregivers*, for details on the program.)



Advocacy Tip

The Community Living Assistance Services and Supports (CLASS) Act includes several programs to support building a larger personal attendant workforce nationwide, and it provides a new option for long-term care coverage. Some members of Congress want to repeal the CLASS program. Let your member of Congress know that new options for long-term care coverage are important and that you support the CLASS Act.

CLASS is not for people who cannot work and who need help today. But for caregivers who have family or friends who might need care in the future, CLASS will make it easier for them to afford the help they need, including helping to pay caregivers.

More Peace of Mind for Caregivers

The health care law includes the **Elder Justice Act**, the **Nursing Home Transparency and Improvement Act**, and the **Patient Safety and Abuse Prevention Act**. These measures establish programs that will help consumers and caregivers make better choices about long-term care options, and they will improve care quality and safety for seniors and people with disabilities. Because of these programs, you can be more confident about the care your loved ones receive when outside help is needed, whether that care is provided at home or in a nursing facility.

- **More Funding for Services that Protect Seniors and People With Disabilities**

The Elder Justice Act provides federal funding for the adult protective services offices that operate in every state. Those offices—which serve seniors and, in many cases, people with disabilities—investigate and sometimes provide legal intervention in instances of neglect, financial exploitation, or abuse. Before the health care law was passed, funding for these offices was often inadequate. With new federal funds specifically allocated to these services, adult protective services offices will be able to do more to protect seniors and people with disabilities.

- **Better Information about Long-Term Care Facilities**

The decision to move a loved one into a long-term care facility can be difficult. If you ever need to make that decision, you will want good information on the options available. The health care law creates programs that will give you more information to make good choices. It includes the Nursing Home Transparency and Improvement Act. This law, among other things, requires that more information be available on Medicare's Nursing Home Compare website. That website gives consumers information on every Medicare-certified nursing home in the country. The law requires the Nursing Home Compare website to post information on nursing home performance, including any problems reported and the facility's plans for addressing them. In 2012, the website will include information on staffing and turnover. This added information will make it easier for you to evaluate safety and quality when selecting a facility, so you can be more confident that you are making a good choice.

■ Greater Protections for People Who Live in Long-Term Care Facilities

The health care law includes several measures that will improve care in long-term care facilities. Through the Elder Justice Act, it authorizes additional funding for state long-term care ombudsman offices. Every state has one of these offices. They resolve nursing home complaints; investigate nursing facilities to ensure that residents are receiving safe, quality care; and they advocate for nursing home improvements in their state. In addition, they educate consumers about their long-term care options. These offices are often underfunded. With the added funding provided through the health care law, they will be better able to serve consumers and protect nursing facility residents.

The health care law also includes the Patient Safety and Abuse Prevention Act. This measure establishes a nationwide program to conduct background checks on applicants for nursing facility jobs that involve direct patient care. The nationwide program is actually an expansion of a seven-state project that has prevented more than 9,500 job applicants with histories of abuse or violent criminal records from working with seniors or people with disabilities.

The Patient Safety and Abuse Prevention Act includes other programs that will improve nursing home quality and safety:

- Requiring that nursing facilities have compliance and ethics programs to prevent and detect civil, criminal, and administrative violations of the law and to improve the quality of care;
- Requiring dementia management and abuse prevention training for nursing facility staff;
- Requiring nursing facilities to provide adequate notification of closure and ensure appropriate placement of residents; and
- Launching a project to oversee large interstate nursing facility chains to determine whether there are safety or quality-of-care issues; results of this project would be made public, and chains where problems are detected would need to develop a plan to address those problems.



Advocacy Tip

Many of the provisions that would better protect people who need long-term services against abuse and improve nursing home care need to be funded through the budget process. These are measures such as the grants to states to enhance adult protective services and to support long-term care ombudsman programs. Advocates can tell their members of Congress that they support improvements in nursing home care, and that the Affordable Care Act should be fully funded so that programs that are designed to protect our seniors and people with disabilities and to improve nursing home quality can move forward.

Good News for Caregivers, Consumers, Businesses, and Communities

The health care law will give you, as a caregiver, more options. There will be more ways to pay for home- and community-based care, which will make it easier for you to find and afford added support to help with caregiving tasks. You will also feel more confident if the person you care for needs to be placed in a nursing facility. The added support that all of these measures provide will help alleviate the stress of caregiving, and that's good news for businesses. Businesses lose an estimated \$33 billion a year due to employee caregiving responsibilities.⁵

The health care law will also give people who need long-term services more options and better quality care. That's good news for everyone.

You Can Play a Role in Making Sure These Changes Happen

All of the added help we've discussed will disappear if the health care law is repealed. Building up the long-term care workforce, establishing more options for home- and community-based care, creating a long-term care insurance program, making improvements in nursing home safety, providing more information on nursing home quality, and instituting greater protections against abuse for those you love—all of this goes away. Even if the law isn't repealed, a lot of measures won't move forward if Congress refuses to provide funds for implementing the health care law, as many members of Congress are trying to do.

If this added help sounds like a good idea to you, let your Senators and Representative know that you support the health care law and funding for its implementation. For more detailed information on the provisions we've discussed here, see the brief, *The Affordable Care Act: Provisions that Will Help Caregivers*.

Endnotes

¹ About 52 million people provide care at some time during a year. Ari Houser and Mary Jo Gibson, *Valuing the Invaluable: The Economic Value of Family Caregiving, 2008 Update* (Washington: AARP Public Policy Institute, November 2008).

² Ari Houser and Mary Jo Gibson, op. cit.; Evercare and National Alliance of Caregivers, *Family Caregivers: What They Spend, What They Sacrifice* (Minnetonka, MN: Evercare, November 2007), available online at http://www.caregiving.org/data/Evercare_NAC_CaregiverCostStudyFINAL20111907.pdf.

³ Department of Health and Human Services, Health Resources and Services Administration, *Nursing Aides, Home Health Aides, and Related Health Care Occupations: National and Local Workforce Shortages and Associated Data Needs* (Washington: Health Resources and Services Administration, February 2004), available online at <ftp://ftp.hrsa.gov/bhpr/nationalcenter/RNandHomeAides.pdf>; Department of Health and Human Services' Office of the Assistant Secretary for Planning and Evaluation, Centers for Medicare and Medicaid Services, and Health Resources and Services Administration, and the Department of Labor's Office of the Assistant Secretary for Policy, Bureau of Labor Statistics, and Employment and Training Administration, *The Future Supply of Long-Term Care Workers in Relation to the Aging Baby-Boom Generation: Report to Congress* (Washington: Department of Health and Human Services and Department of Labor, May 2003), available online at <http://aspe.hhs.gov/daltcp/reports/ltcwork.pdf>.

⁴ For more information on these programs, see the Families USA fact sheet, *Health Reform Provisions that Expand Access to Home- and Community-Based Services (HCBS)*, available online at <http://www.familiesusa.org/assets/pdfs/health-reform/Long-Term-Services-Expanding-Access.pdf>.

⁵ MetLife Mature Market Institute, *The MetLife Caregiving Cost Study: Productivity Losses to U.S. Businesses* (Westport, CT and Washington, D.C.: The MetLife Mature Market Institute and the National Alliance for Caregivers, 2006). Losses take the form of increased absenteeism, lost time at work due to dealing with caregiving issues, and costs related to job turnover when caregiving responsibilities force employees to leave the workforce.



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